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MATERNAL AND CHILD HEALTH

STRATEGY STATEMENT

DATA UTILIZATION AND ENHANCEMENT

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INTRODUCTION

The health status of women and children in the United States and the health care they receive are issues of continuing and growing concern. A review of health status indicators such as infant mortality, low birth weight, childhood mortality rates from injury, and the incidence of child abuse and neglect confirm this disturbing reality. Despite numerous efforts, both public and private, many women and children are not receiving the comprehensive services they need in order to lead healthy and productive lives. The lack of an effectively integrated, financed, and organized health care delivery system that combines both public and private resources is at the core of these problems.

The cornerstone of any effort to solve these health problems at the state and community level is an effective public health infrastructure combined with support from the private practice community and other social support services. Only with such a community-based public-private partnership will we be able to systematically address the health problems of children and families. The Maternal and Child Health Services Block Grant is intended to assist states in the development of an effective MCH infrastructure at the state and local levels. The solution of MCH problems also requires interdepartmental and interdisciplinary collaboration at the national, state, and local levels.

Quantitative and qualitative data collection, analysis, and usage are critical ingredients for effective problem solving and are fundamental to the development of an infrastructure to solve health problems at the state and local levels. Data analysis should be a central component of efforts to identify maternal and child health needs, to design appropriate program interventions, to manage and evaluate those interventions, to monitor progress towards the Healthy People 2000 objectives for women and children, and to monitor the effects of health care reform. These efforts can be categorized by the following seven functions or uses of data: **needs assessment**, **policy and program development**, **evaluation**, **resource allocation**, **monitoring**, **quality assurance**, and **accountability and resource justification**. In addition, data needs for important functions, especially at the local level, related more directly to client care, such as **case management/care coordination** and **billing,** need to be considered. (See Appendix A for definitions.)

Prior to the enactment of the MCH block grant of 1981, state Title V programs and demonstration projects were required to provide information on their activities, objectives, and the clients served. With the initiation of the block grants, states were only required to submit a "Report of Intended Expenditures" and a "statement of assurances" related to Title V activities. Several years ago policy makers and advocates for the improved health of mothers and children realized that the information collected through the block grant reports was inadequate to develop or advocate for services for these groups and to document use and effect of federal funds for maternal and child health services. The passage of OBRA '89 was a first step toward rectifying this situation. OBRA '89 mandated a state-level needs assessment for maternal and child health services based on quantitative and qualitative analysis, the development of an annual state plan to address these needs, and a standardized Annual Report on the implementation of the plan. States have completed their first needs assessments and several Annual Reports. Now it is time, especially with the emergence of numerous health care reform efforts, to have a strategy for the development of a comprehensive approach to address the maternal and child health data needs at all levels.

The overall **mission** of implementing the OBRA '89 data requirements is to improve the health of mothers and children through effective use of data and analysis for decision-making at the local, state, and federal levels. This mission will be achieved through the following **goals**.

1. Analyze local, state and national data to improve needs assessment and performance evaluation and to provide the basis for policy formulation for maternal and child health.

2. Develop a model Maternal and Child Health Information System at state and local levels to meet functional needs at local, state, and federal levels.

3. Enhance capacity at the local and state levels to collect, analyze, and use maternal and child health data to make program and policy development decisions.

4. Enhance the collection, analysis, dissemination, and use of maternal and child health data at the federal level.

This document represents an overview of the ongoing efforts to develop a comprehensive approach for the collection, analysis, use and dissemination of maternal and child health data for the United States and its Territories and Jurisdictions. It is organized around the four goals identified previously. For each goal a number of issues are identified that address needs within the goal area. Some goals will have unresolved issues identified, indicating a need for further discussion. In the development of a plan to address these issues, the use of both quantitative and qualitative MCH data should be considered. Also to be considered is the need for integration of many MCH systems of data collection, analysis, and usage at the state and local levels as well as other non-MCH data linkages.

These efforts are being spearheaded by the Public Health Service through its Maternal and Child Health Bureau (MCHB) and this strategy will guide MCHB and its Maternal and Child Health Information Resource Center (MCHIRC) in developing a strategic plan to achieve these goals. The MCHIRC was established by the MCHB in the Fall of 1991 through a contract with the Public Health Foundation. The Center was funded to strengthen the management and analysis of MCH data for decision making at the federal, state, and local levels. A Panel of Experts (POE) including specialists in the fields of MCH data collection and analysis has been established to advise the Center in developing this MCH Data Strategy. A Federal Interagency Data Work Group (FIDWG) has also been formed to promote use of standard definitions of shared data elements, to share resources and data and to provide leadership in their respective agencies in interagency collaboration.

ANALYSIS OF LOCAL, STATE AND NATIONAL DATA

The MCH Community feels that it is critical to communicate the needs of the nation's women, infants, children, adolescents, and children with special health care needs to MCH policy makers. This information is needed to identify problems, to direct resources needed to resolve them, and to assess the role that the Title V program plays in addressing them.

GOAL 1: Analyze local, state and national data to improve needs assessment and performance evaluation and to provide the basis for policy formulation for maternal and child health.

ISSUE 1.1 OBRA '89 requirement that an Annual Report be submitted to Congress by the Secretary of Health and Human Services.

In order to assure that the Annual Report to Congress is the most useful, the content, design, and preparation of the Report should be considered; detailed guidance to the states for the collection of the required maternal and child health data should be developed; regional summaries should be prepared; and the Report and the regional summaries should be widely disseminated.

ISSUE 1.2 Need for special analyses and studies to improve the needs assessment process, facilitate program performance, and assist in policy formulation for maternal and child health.

The Annual Report to Congress will not meet all the maternal and child health data needs at the local, state and national levels. Such things as the production, updating, and dissemination of additional maternal and child health data, for example *Child Health USA*; fostering the development of MCH

economic analyses; and the design of a system to monitor MCH program impacts and outcomes through sentinel indicators are examples of other activities that should be considered.

MODEL MATERNAL AND CHILD HEALTH INFORMATION SYSTEM TO MEET FUNCTIONAL NEEDS AT THE LOCAL, STATE AND NATIONAL LEVELS

A comprehensive and integrated system of maternal and child health information should address a number of questions and/or problems at the local, state, and national levels on which maternal and child health programs might have some effect. To do this, MCH information will need to address the functions or uses of data noted in the Introduction. These include, but are not necessarily limited to: **needs assessment**, **policy and program development**, **evaluation**, **resource allocation**, **monitoring**, **quality assurance**, **accountability and resource justification**, **case management/care coordination**, and **billing**. (See Appendix A for definitions). As new questions/problems emerge additional information should be able to be added, and information that is no longer relevant deleted, to ensure the **model** MCH Information System is responsive to changing needs.

In addition, the information system should meet a number of mechanical requirements including: **flexibility, minimum duplication and ease of data entry, routine data editing, accessibility for reporting, use of common definitions, ability to link to other related data systems, and facilitation of epidemiological analyses**. Finally, it should allow for the analysis at the following geographical levels, depending on the type of data being collected: **clinic, service provider, zipcode, block, census tract, city/township, county, sub-state planning region, state and federal legislative districts, state, DHHS Region, and United States**. The majority of the functions and mechanical requirements are the same at all three levels, **local, state,** and **national**, but the units of analysis are frequently different. For example, the smallest unit of analysis that is needed at the national level is most frequently county, while the smallest unit at the state level is usually city or township and at the local level it is zipcode or the individual client for patient/client care.

To be comprehensive and meet all the above requirements a model Maternal and Child Health Information System must address data needs at the individual level as well as the aggregate, indicator level. Since there is already a major national effort to address the core data elements for inpatient and ambulatory care services at the individual level by the National Committee on Vital and Health Statistics which is receiving MCH input, initial efforts by the Maternal and Child Health Bureau and the Maternal and Child Health Information Resource Center should center around the development of a set of recommended indicators that will be useful at the national, state, and local levels to address the first seven functions: **needs assessment**, **policy and program development**, **evaluation**, **resource allocation**, **monitoring**, **quality assurance**, and **accountability and resource justification**.

GOAL 2: **Develop model Maternal and Child Health Information System at state and local levels to meet functional needs at local, state, and federal levels.**

ISSUE 2.1 Indicators and related data elements at the *population-level* need to be specified for a model MCH Information System based on data collected at the local and state levels to address the first seven functional areas at the local, state, and national levels.

Given the current situation and the resources available, the development of a recommended set of indicators should be approached by defining a model set of indicators and related data elements that will address the most important questions/problems at the local, state, and national levels on which maternal and child health programs might have some effect. The target audience for these indicators should primarily be federal, state, and local level Title V policy makers and planners, starting with the state Title V agencies and expanding to the local and federal levels. Secondary target audiences include other agencies, legislators, advocacy groups, training programs, managed care organizations, and the private

sector. This **model set** of MCH indicators needs to maximize but not be limited to data that are currently available in automated form at the state and local level in the majority of states. It should include those items required by OBRA '89, the Healthy People 2000 maternal and child health-related objectives, HEDIS (Medicaid), the Partnership Block Grants, reporting requirements of other related federal agencies and any additional data needed to perform the functions noted above, including the development of MCH Report Cards.

This **model set** of MCH indicators needs to be structured to be culturally sensitive and to ensure that data needs are met for each of the following populations: 1) women in reproductive years, 2) infants, 3) children, 4) adolescents, and 5) children with special health care needs. It needs to address the problems in obtaining denominator data for each group (i.e., problems with getting population estimates for the appropriate age and racial groups between censuses), the lack of service data for each group and the lack of outcome data especially for children, adolescents and children with special health care needs. Whenever indicators are included for which data are not readily available a plan for collecting these data needs to be developed.

ISSUE 2.2 A recommended set of data elements at the *individual-level* that should be included in a model MCH Information System at the local level, to address all nine functional areas at the local, state, and federal levels, including the last two directly related to client care is needed.

As mentioned before, activities that address this issue need to build on the work of the National Committee on Vital and Health Statistics to define the core data elements for inpatient and ambulatory care services at the individual level.

ISSUE 2.3 To facilitate production of useful indicators and enhance client care at the individual level, data from various service programs and between different related agencies (such as disability, Medicaid, UB-92, SSA, Head Start, public education, mental health, and substance abuse) needs to be able to be shared and linked, as well as aggregated at the local, state, and national levels to support program development, monitoring and evaluation and to fulfill the requirements for Congressional reporting.

Given that unique identifiers are rarely available between multiple data sets, other mechanisms for linking files need to be considered. In addition guidelines for the automation of data need to be developed that will facilitate data sharing.

ISSUE 2.4 All material developed related to the model MCH Information Systems and related analysis guidelines and analytic tools need to be disseminated at the state and local levels.

Electronic dissemination, over the Internet, as well as disseminating hard copies should be considered.

UNRESOLVED ISSUE 2.5

A system to assure that the model MCH Information System will be modified to address emerging questions/problems that require additional data needs to be developed. Implementation of health care reform and revisions of objectives for the nation should be tied to this system.

LOCAL AND STATE CAPACITY TO COLLECT, ANALYZE, AND USE MATERNAL AND CHILD HEALTH DATA

There is currently great diversity in the capacity of local and state agencies to collect, analyze, and use maternal and child health data. Local and state agencies with less than adequate capacity need to be assisted in obtaining the resources needed to minimize discrepancies in capacity. The general approach to be used will be one to identify the needs and resources, starting at the state level and expanding to the local level; development of analysis tools to assist with needs assessment, planning, and evaluation; and implementation of coordinated consultation, technical assistance, and training activities. The first two aspects are reasonably self-explanatory but some definition of what is meant by consultation, technical assistance, and training is necessary.

The terms that cause the most confusion are **consultation** and **technical assistance**. For the purposes of this document, **consultation** is the process of using experts to assist individuals/organizations to identify/define and/or redefine problems/issues; prioritize these problems/issues and determine the level of personnel and financial resources to be allocated to address these problems/issues. Under this definition, consultation is seen as the use of experts in the needs assessment process. **Technical assistance** would then be the process of providing individuals/organizations with expert knowledge, skills, and products in order to assist them in addressing their identified problems/issues, thus supporting the needs assessment/consultation process. Both of these activities are "client-centered," (i.e., individualized to meet particular needs and situations of the client organization/individuals). **Training** on the other hand is curriculum based. It is an activity that is designed to enhance the knowledge and skills of trainees in predefined areas to a predefined level of competence. A training program involves providing knowledge, skills, and materials that can be applied to a broad range of situations, therefore making it generalizable. Training can be a form of technical assistance, if the problem/issue to be addressed happens to be the subject of a preexisting training program.

GOAL 3: **Enhance capacity at the local and state levels to collect, analyze, and use maternal and child health data to make program and policy development decisions.**

ISSUE 3.1 The capacity at the local and state levels to collect, analyze, and use maternal and child health data needs to be identified.

Input should be obtained from the State MCH/CSHCN Directors, the Association of Maternal and Child Health Program Data Committee, and the Association for Public Health Statistics and Information Systems. Related meeting summarizes and survey reports, such as the MCHIP DATA Conference '92 and Project CAN-DO should be reviewed. Finally, MCHB's own projects funded in the area of data development and analysis should be reviewed as potential resources.

ISSUE 3.2 Need for financial resources to develop, modify, maintain, link, and use data at the local, state and national levels.

Along with the provision of additional funds, such things as reallocation of Title V and non-Title V dollars from administration and service to data development and analysis activities and the pooling of data development and analysis funds between projects and programs should be considered.

ISSUE 3.3 Need for skilled personnel for the implementation, maintenance, and use of a MCH/CHSCN data set.

In addition to the continuation and enhancement of the MCH training programs in Schools of Public Health, such things as the development of a graduate student internship program at the state/local level, coordinated provision of intensive long-term as well as short-term technical assistance, and increasing the number of CDC/MCHB epidemiologists to the states could address this issue.

ISSUE 3.4 Need for training for current state and local staff to enhance skills in implementing, maintaining, and using the MCH data set.

Mechanisms for skills building at the regional, state and local levels as well as a national plan for their implementation needs to be developed, taking into consideration the difficulty some states have in supporting travel out-of-state.

ISSUE 3.5 Confidentiality concerns at the state and local level related to the release of information.

In addressing this issue, states and other groups (e.g. National Center for Health Statistics, Association for Public Health Statistics and Information Systems, Midwest Maternal and Child Health Data Improvement Project [MMDIP], Youth Law Center, National Center for Service Integration, state and local immunization registry systems, etc.) that have successful strategies related to sharing information between agencies and programs should be identified and a description of these successful strategies disseminated.

ISSUE 3.6 Need for linkage of data systems (both retrospective and prospective) within and between agencies for:

- linking data from multiple sources of care e.g., Title V, Medicaid, and WIC;
- linking service and outcome data;
- case management/care coordination; and
- tracking and follow-up.

This is costly and complex since there is no unique identifier that is used by all data systems and the hardware/software used is so diverse. This problem is somewhat lessened with the ongoing advances in the technology of information systems. Methods of getting at this information other than through linkage should also be investigated.

ISSUE 3.7 Need for user friendly and cost-efficient electronic communications among all state and local MCH, CSHCN, Health Statistical Directors, and their staffs.

Available electronic communications through state government operated systems, university-based systems, private telecommunications-service providers, and CDC's PC-Wonder needs to be made available to all state MCHB-funded projects and Health Statistical Directors.

ISSUE 3.8 Need to explore how other, already developed needs assessment techniques can be applied to MCH/CHSCN data collection and analysis at the state and local level and develop new techniques as needed.

With the current emphasis on needs assessment among MCH/CSHCN programs, many groups are in the process of developing needs assessment tools. To assure the that efforts are not duplicated, they need to be coordinated and based on work that has already been done in this area, such as CDC's Assessment Protocol for Excellence in Public Health (APEX-PH).

ISSUE 3.9 Need for enhancing the capacity of state and local policy staff to interpret and/or conduct economic evaluations of maternal and child health programs.

With the proliferation of health care reform at the state and local levels and the dwindling dollars to pay for health care, the area of economic analysis has moved to the forefront. Much work has been and is currently being done in this area but in many cases it is presented in ways tha